



from cells to community: solutions for spinal cord injury

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Long-term outcomes of individuals born with arthrogryposis.

Dear Participant,

You are invited to participate in this survey if you have been diagnosed with arthrogryposis and are over the age of 19 yrs. Researchers from the University of British Columbia in Vancouver CANADA, are conducting a research study to look at the long term outcomes of individuals born with arthrogryposis. This study has been funded in part by the Rare Diseases Foundation in Vancouver.

Arthrogryposis Multiplex Congenita (AMC) is a condition where primarily the limbs have significant limitation in motion at birth. Many individuals undergo many surgeries and extensive physiotherapy to improve range of motion. Physicians and researchers from around the world agree that there is still little known about what treatment works best for long term function. We propose the largest international study to determine what happens to the long-term health (>19 yrs of age) of individuals living with AMC, using an online survey and an *optional* additional telephone interview. We as researchers from the University of British Columbia in Vancouver, Canada are very interested in learning more about the natural progress and best therapies for various types of AMC.

If you participate in this survey, your data would be entirely anonymous and confidential. If you wish to receive results when the study is done, or wish to participate in the telephone survey where we will ask more questions specific to your type of AMC, please identify yourself at the end of the survey.

If you wish to participate in this research study and are comfortable with the procedures described in this letter, please complete the online survey as best you can (**survey link from GRP here**). If you do not have access to the internet or would just prefer to do it on the paper, please complete questionnaire and send via mail to the address at the top of this page. You may answer all questions or only those you feel comfortable completing. All data is kept confidentially and no personal identifiers are used to link to your information. By completing this survey we are assuming your consent for participating in this study.

We thank you for your interest and time to participate in this study.

Sincerely,

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